

Cynulliad Cenedlaethol Cymru
Y Pwyllgor Iechyd, Gofal Cymdeithasol
a Chwaraeon
Ymchwiliad i Gilead Sciences
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Ymateb gan | Evidence from: Gilead Sciences

National Assembly for Wales
Health, Social Care and Sport
Committee
Inquiry into Hepatitis C

Gilead Sciences is a research-based biopharmaceutical company that discovers, develops and commercialises innovative medicines in areas of unmet medical need. We strive to transform and simplify care for people with life-threatening illnesses around the world. Gilead's portfolio of products and pipeline of investigational drugs includes treatments for HIV/AIDS, liver diseases, cancer, and inflammatory and respiratory diseases. Gilead has three sites in the UK: our international regulatory headquarters in Cambridge, our commercial office in London, and our EMEA regional office in Uxbridge. Together people working from these sites provide approximately 1,000 jobs in the UK, with a portion of the work force based locally across Wales, England, Scotland and Northern Ireland.

Over the past 3 years Gilead has been working in partnership with multiple stakeholders across Wales supporting educational initiatives with a focus on the development of simplified Hepatitis C care pathways across a variety of diverse community based settings. The key aim of this partnership has been to increase access to testing & improve linkage to care and treatment.

Summary

Gilead Sciences welcomes the opportunity to contribute written evidence to support the inquiry into Hepatitis C, being undertaken by the National Assembly's Health, Social Care and Sport Committee. In light of the commitment of both the Assembly and Welsh Ministers for Wales to achieve the World Health Organization's (WHO) 2030 elimination target for Hepatitis C, we feel that this inquiry is happening at an opportune time to review progress and examine what needs to happen next.

While significant progress has been made, it is clear that more needs to be done to treat those with Hepatitis C if the WHO's target is to be met. However, we believe that Wales has many of the tools in place and that the Welsh Government should actually set a more ambitious target. If all parts of the health system work in partnership, we believe that Wales has the capacity and capability to eliminate Hepatitis C several years earlier than the WHO target.

In terms of prevalence, Public Health Wales (PHW) estimates that about 12,000 or 0.4 per cent of the population, are living with the Hepatitis C virus (HCV) ⁱ. Yet, the exact figure is unknown because there are so many people who are undiagnosed; the Hepatitis C Trust estimate that 50% of people who have the virus are undiagnosed ⁱⁱ. Groups that may be at risk of this are:

- People who inject drugs (PWIDs) which includes current and former users and those who use Image and Performance Enhancing Drugs (IPEDs)
- Prisoners
- People seeking asylum, homeless and Migrant populations
- People who have had surgery and medical procedures in countries of higher prevalence

For the past four years we have engaged with Assembly Members, Welsh Government officials, clinicians, third sector and patient groups to understand the personal health needs of each of these very different groups, in a bid to drive a campaign aimed at improving the overall treatment rates of people with Hepatitis C; in particular, raising awareness of:

- the role of testing and treatment in multiple settings leading to cure
- the importance of public awareness to identify and treat more people
- the WHO target of eliminating Hepatitis C by 2030.

During this time Gilead have worked hard to bring together interested parties and key stakeholders to discuss progress, identify challenges and agree actions to support delivery of the elimination target of 2030. Examples of this include:-

- Support of Assembly Members in a cross-party debate calling for Welsh Government to reaffirm its support for the 2030 elimination target.
- Three roundtable discussions bringing together AMs, healthcare professionals, third sector and patient groups to discuss current challenges and propose solutions
- A 'patient voice' campaign launch ("I'm worth....."
<https://www.imworth.co.uk/>)

In examining the terms of reference for this inquiry, we have attempted to highlight and build upon, the positive action that the past year has witnessed, including where there are opportunities to improve.

The Committee's remit for this inquiry

We welcome the terms of reference set by the Committee and would like to offer the following observations:

Meeting the requirements of the Welsh Health Circular

The publication of the Welsh Health Circular (WHC/2017/048) was a welcome development following the Assembly debate on the elimination of Hepatitis B and C in June 2017. This was the first opportunity for Welsh Ministers to set out their expectations to Health Boards and, in doing so, is an important step. One of

the challenges, however, is that an elimination target for 2030 is hard to measure without a specific delivery plan setting out expectations and key actions, resources and measurements to ensure that we stay on course.

This year, Gilead has worked with clinicians and IQVIA™ to undertake incidence and prevalence modelling through to 2040 to understand how many patients need to be treated on an annual basis to ensure the elimination target is met. The current target, agreed between Wales' Blood Borne Virus (BBV) lead consultants and NHS Wales, has an agreed patient treatment figure of 900 patients per annum from 2016-2021. You will see from figure 1.1 in the appendices ("Treatment figures since 2011") that despite the best efforts of the Welsh BBV community, the annual target is yet to be met

Figure 1.2 shows the treatment strategies modelled. Figure 1.3 shows the number with chronic HCV infection and figure 1.4 shows the incidence of chronic HCV infection. Even if the current target (900 patients per year) were met, Wales would still miss the elimination target by several years. These data sets show that the 900 patient current target should be the minimum annual target for NHS Wales and that treatment numbers should rise to between 1200 and 1400 per year.

In order to deliver these numbers, it is clear that a specific, measurable national delivery plan is needed – which cascades down to Health Boards – so resource implications can be properly assessed at Health Board level and maximum effort is concentrated on delivery of performance (see example, *Together for Mental Health*, the Welsh Government's the 10 year strategy 2012 – 2022).

Whilst the Welsh Government's *Together for Health* strategy includes a Liver Disease Delivery Plan, there is nothing specific enough to support the drive towards the elimination target of 2030 and we recommend that the Welsh Government consider how to translate ambition into measurable delivery. It is important to note that even putting in place plans to meet a 2030 target will leave Wales with a lower ambition than NHS England, Scotland and Ireland, all of whom are targeting elimination well before 2030. While ensuring that the existing target can be met must take priority, we would support a higher level of ambition from the Welsh Government to drive towards elimination ahead of 2030.

Recommendation: That the Welsh Government issue a new Welsh Health Circular with detailed measures and clear milestones delivered in line with an annual timetable which ensures elimination of hepatitis C is achieved by 2030 (at the latest). The circular must be underpinned by a comprehensive elimination plan and a clear division of responsibilities down to Health Board level with a mandatory reporting mechanism to monitor performance.

Raising knowledge and awareness of Hepatitis C

The question of how knowledge and awareness of the public and health professionals of HCV can be increased is one of the regular areas of discussion during our round table events. It is evident from stakeholder feedback that there

are two key challenges that need to be overcome via increased knowledge and awareness raising:

- **Overturning negative perceptions about testing and treatment** – that the new treatment regimes are much easier to take than previous interferon treatment programmes and that the cure (Sustained Virological Response - SVR) rate is very high.
- **Normalising the condition** – while progress has been made with healthcare professionals and the public, there is still a significant level of stigma still attached to the condition.

The majority of stakeholders believe there is a need for a multi-faceted public health campaign, backed by Government and utilising third sector organisations, GP surgeries and pharmacies. If we are to reach those currently not engaging, then consideration should be given to a publicly funded media programme. Gilead has been supporting a patient ambassador programme through the “**I’m Worth...**” campaign, which has been available in Wales over the last 18 months, whereby patient Ambassadors are trained and utilised by clinical teams to share their journey with health professionals and others who are at risk of potential infection. The success and growth of this programme clearly indicates that there is a great opportunity to increase and utilise the patient voice to encourage others to get tested and treated.

There are a number of hard to reach groups in Wales, like those in prison, the homeless population and PWIDs, who can have chaotic lifestyles. While progress is being made to reach out to these groups, we have concerns about the fragmented nature of some of that engagement, as well as the capacity of healthcare and third sector staff to meet the required level of demand. We will address those concerns in the next section on programme viability.

Recommendation: The Welsh Government develop, coordinate and fund a co-produced, multi-faceted national awareness campaign with PHW, the third sector, patient ambassadors and other key stakeholders (eg: Pharmaceutical companies) to target multiple at risk groups.

The long-term viability of treatment programmes

Testing and treating more people uses more resources. Current programmes that are reliant on staff volunteering out of hours and delivering over and above regular workload are simply not sustainable in the long term. To reach the 2030 elimination target there must be a Health Board budget committed to resourcing treatment programmes in multiple community based settings. This will require both the NHS and its partners to be clear in how resources will match expectations and how progress will be measured.

There are already multiple programmes and projects, many in pilot form, that are being successfully implemented in Health Boards across Wales (many of these already supported by grants from the Pharmaceutical Sector). These need to be

“scaled up” and delivered nationally to ensure equitable services are open to all patients in Wales.

In prisons, there has been progress with opt-out testing, where we have seen an overall average testing rate of 30% (from 10%) in some prisons. However, the goal is to make prisons HCV free, which is achievable but requires additional resource for staff. While testing in prisons is improving, two key challenges remain:- current work force capacity and throughput of prisoners (the speed of through-put and transfer of prisoners can be challenging, so there is a need to get prisoners tested and on a care pathway quickly before they are moved). The need for a BBV nurse in each prison (like the one based in Parc Prison Bridgend) will encourage normalisation of BBV testing in the prison setting, and allow inmates to be tested and treated quickly. Without additional clinicians on the ground, stemming the reservoir of infection while prisoners are in custody will not be achieved.

Another excellent example of a collaborate outreach is project in the Salvation Army Night Bus project in Cardiff and Vale UHB. Reaching the homeless population can be especially hard as traditional services cannot always engage effectively. However, clinical staff in Cardiff and Vale proactively partnered with the Salvation Army, Cardiff City Council, the Wallich and the Huggard, to go out on one of the homeless night buses, voluntarily doing so beyond their hours of work, to promote the testing for Hepatitis C and the immediate treatment of the disease. This pilot scheme tested 37 homeless people, 7 of those tested HCV positive, 6 of those have now been treated, with one other person being followed up for additional testing. The key success factors here were multi agency working, patient peer mentoring and crucially, the opportunity to screen and treat simultaneously in one place at one time. However, the fundamental factor is the longevity of such a programme where clinicians are giving up their time voluntarily to go over and above what they are doing during their day jobs.

It clearly demonstrates the need for additional resource and the need for a co-ordinated response across agencies and organisations to capture those potential patients that are slipping through the net.

For PWIDs, accessing services is more challenging. These people lead chaotic lifestyles and need testing and treatment to be easy to access, with no stigma attached, and used as a stepping stone to a more healthy and stable life. Further development of services offering testing in multiple settings (ie: Needle exchange), normalisation of an annual testing cycle and treatments available in community are needed to make it simple and easy to treat this population.

Recommendation: The Welsh Government should ensure that funding is available – either via a central budget, or clear direction to Health Boards - to enable Health Boards and third sector organisations to fund delivery of specific elements of the new Welsh Health Circular (ie: delivery plan) and ensure increased patient numbers can be identified and treated on an annual basis (to meet the elimination target of 2030).

The scope to increase community-based activity e.g. the role of community pharmacies

The network of both the 700+ community pharmacies and also GP surgeries offers an important opportunity to get the message out to people who may have risk factors and need access to testing and treatment. In light of the diversity of population groups who are infected, using professionals in a community based setting must be achieved if the elimination target is to met.

In September 2018, a national community pharmacy lead was appointed to support roll out of test and treatment service across Wales. A service specification for payment of community pharmacies to deliver testing has already been developed and is being reviewed by the National Enhanced Services Board imminently. It is important that the momentum on this initiative continues and a suitable, speedy solution for access to medicines in a community pharmacy setting is sought quickly. This ensures that those identified with HCV infection can be treated quickly without being “lost”.

Community Pharmacies are a key stakeholder in accessing multiple sectors of community that do not access other health services and would otherwise remain invisible. The importance of national leadership of this initiative cannot be underestimated – community pharmacists are independent contractors and need to be engaged and supported in their role to ensure this part of the strategy is successful.

Gilead have facilitated links between Tayside (Scotland) and Wales to allow sharing best practice on delivery of a test and treat service in community pharmacy setting. Lessons can be learned from this model where Health Boards “pump prime” payment to community pharmacies to support cash flow

- payment for medicines and service.

Gilead has also been trialling some GP education and outreach in England to mobilise GPs to take action in eliminating HCV, including an online, email and print campaign. We have also funded a one-day training programme and e-learning for GPs which was initially rolled out to 120 delegates in 5 locations across England. With GP surgeries increasingly seen as opportunities to tackle a variety of health issues collaboratively through the roll out of GP clusters, we will be looking to use experience of our GP work in England to support similar initiatives in Wales.

Recommendation: The Welsh Government should:

- Ensure that delivery of the community pharmacy testing service is implemented across all Health Boards in Wales in a timely manner.
- Work with NHS Procurement and Pharmaceutical Company stakeholders to overcome barriers and agree a process to enable safe and secure access to hepatitis C medicines in the community setting (either community pharmacy or drug treatment centres).

Conclusion

Wales has made considerable strides in the putting the right policy framework in place and following through with funding to support a national test and treatment programme. In an environment where health policy is usually contextualised in terms of disease management, resources and waiting times, it is exciting for all of us to be participating in delivering the elimination of a disease where there is:

- A clear national ambition and underpinning plan
- A highly functional network of clinicians
- Equitable and transparent access to treatment, where decisions are clinically led
- Access to treatment with no waiting list
- Commitment from clinicians to look at new ways of delivering services

However, there is more to be done if Wales' is to push forward its ambition for elimination. While it is committed to the WHO target, other UK administrations are setting targets ahead of 2030. NHS England has set a target of 2025, and Scotland 2027 and our near European neighbours, The Republic of Ireland, has set a target of 2026. We think the Welsh Government should be looking to eliminate Hepatitis C by 2030 at the very latest, and putting in place resources and key milestones to achieve elimination as quickly as possible. We believe the recommendations in this paper will enable the Government with its partners to take those key steps and make elimination a reality.

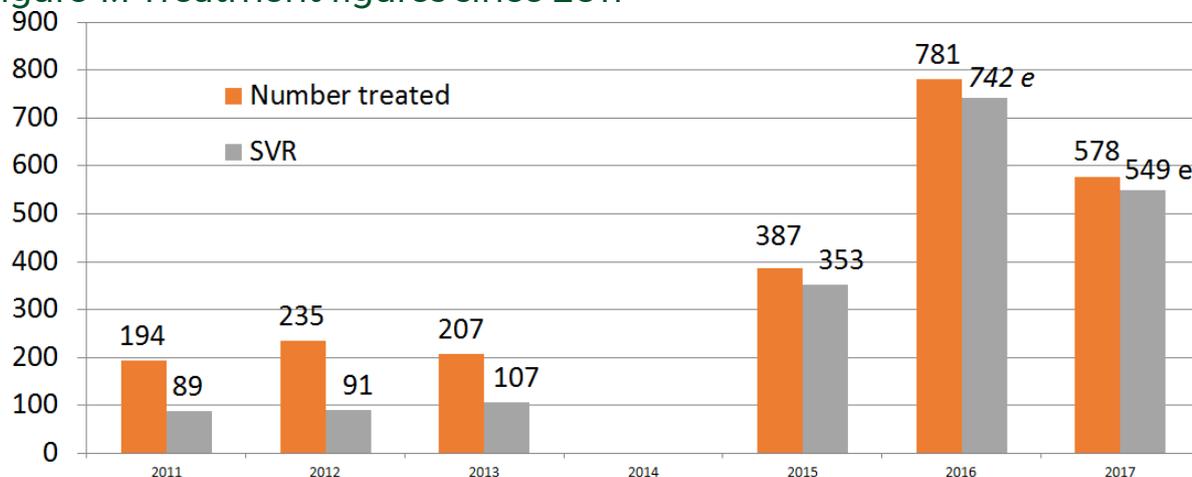
References

ⁱ Public Health Wales website (accessed December 2018) - <http://www.wales.nhs.uk/sitesplus/888/page/43746>

ⁱⁱ <http://www.hepctrust.org.uk/campaigning/campaigning-wales> Appendix - attached

APPENDIX: National Assembly for Wales Health, Social Care and Sport Committee Inquiry into Hepatitis C

Figure 1.1 Treatment figures since 2011



*2014 – no data available

Figure 1.2 Treatment strategies modelled



Figure 1.3 Number with chronic HCV infection (Wales)

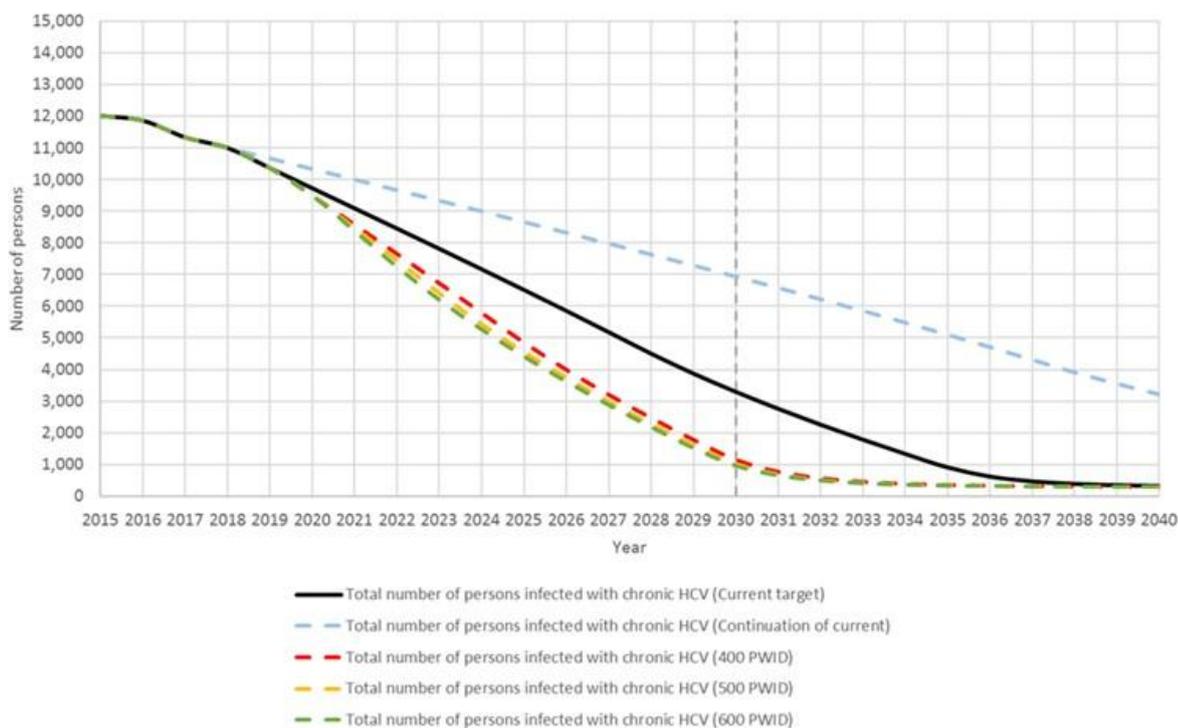
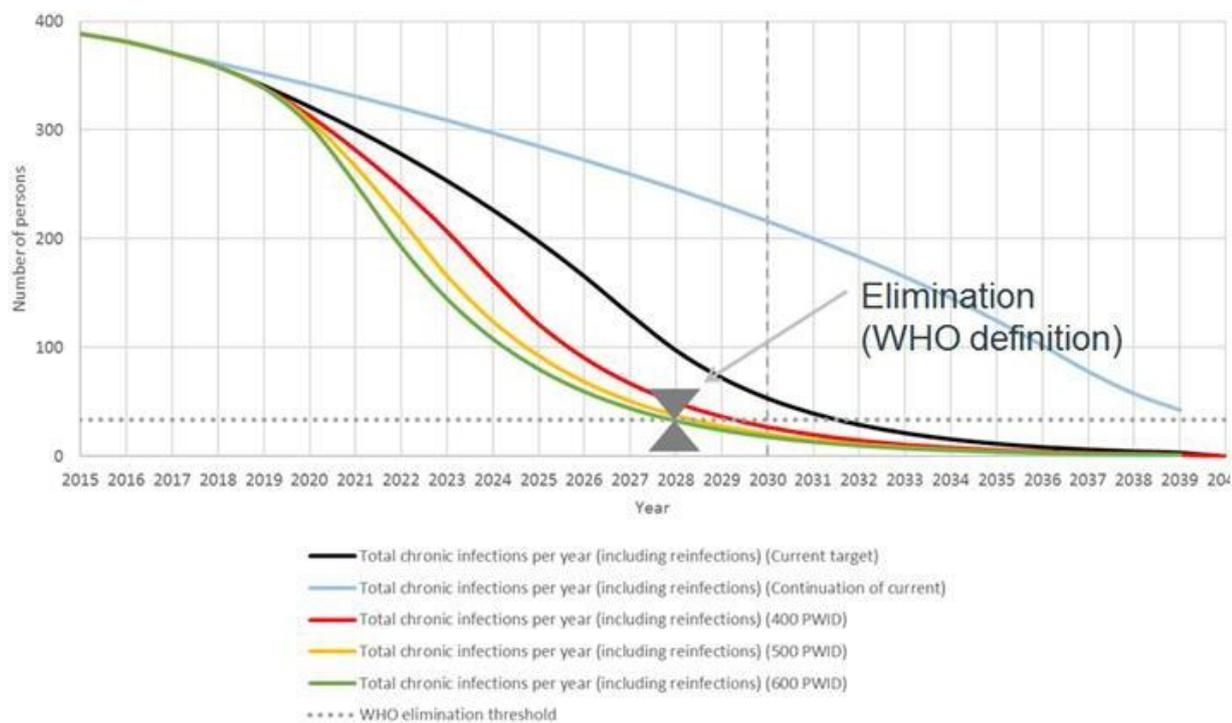


Figure 1.4 Incidence of chronic HCV infection – annual (Wales)



References:

Figure 1.1 – data presented at “Road to elimination; one year on” Job Number: 000/UK/18-10/NM/2116 Date of preparation: 14 October 2018